Measuring outcomes in pain management

Kathy Eagar  
*University of Wollongong, keagar@uow.edu.au*
Measuring outcomes in pain management

Abstract
This paper will draw on the experiences of two national clinical benchmarking and patient outcome measurement centres - the Palliative Care Outcomes Collaboration (PCOC) and the electronic Persistent Pain Outcomes Collaboration (ePPOC) - to identify key issues in measuring patient outcomes. Outcomes reported through both centres will be presented and the lessons from both centres will be discussed.

Keywords
pain, measuring, outcomes, management

Publication Details

This conference paper is available at Research Online: https://ro.uow.edu.au/ahsri/612
Measuring Outcomes in Pain Management

Professor Kathy Eagar
Director,
Australian Health Services Research Institute

50 Shades of Pain
Brisbane December 2014
Overview

◆ Why measure and benchmark outcomes
◆ A brief introduction to AROC, PCOC and ePPOC
◆ How we measure outcomes in PCOC and ePPOC
◆ Some results to illustrate the ideas
◆ What we have learned
AHSRI clinical repository & benchmarking initiatives

Australasian Rehabilitation Outcome Centre (AROC) Started in 2002. Participating services: 372

Palliative Care Outcomes Collaboration (PCOC) Started in 2005. Participating services: 130

electronic Persistent Pain Outcomes Collaboration (ePPOC) Started in 2013. Participating services: 33
Why measure patient outcomes?

◆ For research and clinical learning
  – What works for which patients

◆ To support communication
  – Between clinicians and across sector (common language)
  – Between clinicians and patients

◆ For use in clinical practice
  – To assess and monitor patient progress and outcomes
  – To demonstrate to purchasers that treatment is effective and value for money
A development cycle for outcomes assessment and benchmarking

But it’s a bit more chaotic in practice!
One off studies

Outcome studies

Culture Change
Routine measures

Outcome studies → Routine outcome measures → Culture Change
Establish systems

Outcome studies → Routine outcome measures → Routine outcome systems (training, data collection protocols & processes) → Culture Change
Measurement

- Outcome studies
- Routine outcome measures
- Routine outcome systems (training, data collection protocols & processes)
- Culture Change
- Performance measurement
Outcome studies → Routine outcome measures → Routine outcome systems (training, data collection protocols & processes)

Culture Change

Feedback → Performance measurement

Feedback
Benchmarking

Outcome studies

Routine outcome measures

Routine outcome systems
(training, data collection protocols & processes)

Culture Change

Benchmark
(use the data to identify best practices and then implement them)

Feedback

Performance measurement
The benchmarking cycle

Outcome studies

Routine outcome measures

Routine outcome systems (training, data collection protocols & processes)

Evaluate & refine (measures & systems)

Benchmark (use the data to identify best practices and then implement them)

Culture Change

Feedback

Performance measurement
PCOC and ePPOC
The Palliative Care Outcomes Collaboration (PCOC)

◆ Initiated by federal Department of Health

◆ Four university collaboration

◆ Scope is multidisciplinary specialist palliative care services (public, private and NGO) in Australia
PCOC collaboration

- Australian Health Services Research Institute University of Wollongong (Professor Kathy Eagar)
- Institute of Health & Biomedical Innovation Queensland University of Technology (Professor Patsy Yates)
- Department of Palliative & Supportive Services Flinders University (Professor David Currow)
- Cancer & Palliative Care Research & Evaluation Unit University of Western Australia (A/Professor Claire Johnson)
The electronic Persistent Pain Outcomes Collaboration (ePPOC)

- Initiated by Faculty of Pain Medicine
- Australian Pain Society, PainAustralia and other stakeholders all involved in development and implementation
- Scope is multidisciplinary chronic pain management services (largely hospital outpatient) in Australia and New Zealand
How PCOC and ePPOC work

◆ Work with services to incorporate patient outcome measures into routine practice
◆ Provide ongoing support through training and assistance with IT
◆ Analyse the data and provide feedback on the results to individual services - reports every 6 months
◆ Facilitate benchmarking with other services
◆ Assist services with practice quality changes – Quality Improvement Facilitators (QIFs)
Approach to pain management

Pain management is core business in both palliative care and chronic pain management, however strategies and approaches differ

**PCOC**
- Aim is for patient to be pain-free
- Opioids are used routinely in clinical practice

**ePPOC**
- Aim is often to help patient live with the pain
- Goal is to minimise use of opioids
Assessment tools

**PCOC**
- PC Phase
- SAS
- PCPSS
- AKPS
- RUG-ADL

**ePPOC**
- Brief Pain Inventory (BPI)
- Depression Anxiety Stress Scale (DASS21)
- Pain Self Efficacy Questionnaire (PSEQ)
- Pain Catastrophising Scale (PCS)
Assessment tools (cont.)

- **SAS** – pain, sleeping, appetite, nausea, bowel, breathing, fatigue
- **PCPSS** – pain, psychological / spiritual, family / carer, other physical symptoms
- **AKPS and RUG-ADL** – function (ADLs)
- **BPI** – pain intensity and interference
- **DASS21** – depression, anxiety and stress
- **PSEQ** – confidence in ability to do activities despite the pain
- **PCS** – thoughts and feelings related to patient’s pain
Patient rating and proxy ratings

PCOC
◆ Varies by service and setting but about:
  – Patient – 50%
  – Family / carer – 40%
  – Clinician – 10%

ePPOC
◆ All assessment tools are patient rated (with parents rating young children)
Patient outcome measures - PCOC

- Time between ready for care and episode start
- Time in unstable phase
- Change in pain and symptoms (from start to end of phase)
  - Adjusted for casemix
Unit of counting - PCOC

◆ Episodes of care broken up into Palliative Care Phases (stage of illness):
  – Stable
  – Unstable
  – Deteriorating
  – Terminal

◆ The ‘outcome’ is the change from the beginning to the end of each phase
Patient outcome measures - ePPOC

- Pain interference, intensity and frequency
- Mood and cognition
- Opioid and other drug use
- Health service utilisation (e.g. ED, hospital admissions)
- Ability to work/study
Unit of counting - ePPOC

- Outcomes measured from:
  - Referral to episode start
  - Episode start to episode end
  - Start to end of each treatment ‘pathway’ within an episode
    - Group program, individual appointments
  - 3 months after discharge from the service
A few examples of patient profiles and outcomes

PCOC
<table>
<thead>
<tr>
<th>Tool</th>
<th>Problem/ Symptom</th>
<th>% of phases beginning</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Absent/ mild</td>
<td>Moderate/ severe</td>
</tr>
<tr>
<td>SAS</td>
<td>Pain</td>
<td>72.4</td>
<td>27.6</td>
</tr>
<tr>
<td></td>
<td>Difficulty sleeping</td>
<td>83.9</td>
<td>16.1</td>
</tr>
<tr>
<td></td>
<td>Appetite</td>
<td>72.5</td>
<td>27.5</td>
</tr>
<tr>
<td></td>
<td>Nausea</td>
<td>90.2</td>
<td>9.8</td>
</tr>
<tr>
<td></td>
<td>Bowel</td>
<td>84.5</td>
<td>15.5</td>
</tr>
<tr>
<td></td>
<td>Breathing</td>
<td>77.8</td>
<td>22.2</td>
</tr>
<tr>
<td></td>
<td>Fatigue</td>
<td>43.0</td>
<td>57.0</td>
</tr>
<tr>
<td>PCPSS</td>
<td>Pain</td>
<td>76.8</td>
<td>23.2</td>
</tr>
<tr>
<td></td>
<td>Psychological/spiritual</td>
<td>75.4</td>
<td>24.6</td>
</tr>
<tr>
<td></td>
<td>Family/carer</td>
<td>67.2</td>
<td>32.8</td>
</tr>
<tr>
<td></td>
<td>Other symptoms</td>
<td>60.1</td>
<td>39.9</td>
</tr>
</tbody>
</table>
Moderate/severe pain improving to no or mild pain
Change in symptoms relative to the baseline national average.

- Pain
- Nausea
- Breathing problems
- Bowel problems

Data from July-December 2009 to January-June 2014.
Change in symptoms relative to the baseline national average

- Family/carer
- Psychological/spiritual
- Other symptoms

Graph showing trends from Jul-Dec 2009 to Jan-Jun 2014.
A constant theme - unexplained variation

No matter what the measure, we find significant variations between services that we are working to understand and reduce

Some examples...
% of inpatients with moderate/severe pain at phase start and absent/mild at end
% of home patients with moderate/severe pain at phase start and absent/mild at end
60% with mod/severe pain at start have absent/mild pain at end
A few examples of patient profiles and outcomes

ePPOC
ePPOC – some early data

- 2853 adult patients
- Referral profiles at this stage
- Limited outcome data
Top 5 pain sites

Percent of patients

- Back: 40%
- Arm/shoulder: 10%
- Leg: 5%
- Neck: 5%
- Head: 5%
Top 5 causes of pain

- Injury at work/school
- No obvious cause
- After surgery
- Other
- Related to another illness

Percent of patients
Top 5 comorbidities

- Depression/Anxiety
- Arthritis
- High blood pressure
- Diabetes
- Heart disease

Percent of patients
Pain history
(how long pain has been present)

Percent of patients

< 3 mths  3-12 mths  1-2 yrs  2-5 yrs  > 5 yrs
<table>
<thead>
<tr>
<th>Measure</th>
<th>Ave score</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>BPI average pain</td>
<td>6.3</td>
<td>Moderate</td>
</tr>
<tr>
<td>BPI pain interference</td>
<td>7.0</td>
<td>Max score 10</td>
</tr>
<tr>
<td>DASS depression</td>
<td>20.0</td>
<td>Moderate (21 = Severe)</td>
</tr>
<tr>
<td>DASS anxiety</td>
<td>13.9</td>
<td>Moderate (14 = Severe)</td>
</tr>
<tr>
<td>DASS stress</td>
<td>20.7</td>
<td>Moderate</td>
</tr>
<tr>
<td>PCS</td>
<td>29.3</td>
<td>High (&gt;30 = Severe)</td>
</tr>
<tr>
<td>PSEQ</td>
<td>21.2</td>
<td>Moderate (&lt;20 = Severe)</td>
</tr>
</tbody>
</table>
81% - pain affects hours patient is able to work or study
84% - pain affects type of work able to do
89% - pain is always present
64% - patients using opioids on >2 days per week
Clinically significant change

◆ “... a difference is a difference only if it makes a difference” (Daniel Huff, 1954, p.58)

◆ Clinically significant change indicators developed for each of the ePPOC tools and used:
  – at the patient level (is this change of X on tool Y a meaningful change for my patient?)
  – in reports (e.g. % of patients who made clinically significant change)
Clinically significant change

For example, on the BPI average pain item:

≥ 10% = minimally important change
≥ 30% = moderately important change
≥ 50% = substantial clinically important change
Clinically significant change – BPI average pain

- 15.4% of patients did not change
- 38.5% made minimally important change
- 30.8% made substantial clinically important change
What we have learned

- More use of patient reported measures as the three centres have developed
- Sustainability depends on having clinically useful measures capable of routine collection
- Importance of measuring and reporting clinically significant change
- Importance of national approach and Quality Improvement Facilitators for quality improvement, not just for training
Conclusion

◆ The jury is in - measuring patient outcomes and benchmarking has been demonstrated to drive improvements in patient care

◆ But... PCOC experience is that pain has improved much less than other symptoms
  – Too early to draw conclusions for ePPOC

◆ There is much more to do
  – Improving the evidence base
  – Implementing the evidence
  – Learning from each other
Further information

AHSRI - http://ahsri.uow.edu.au
